

Practice Improvement Protocol 16

PERVASIVE DEVELOPMENTAL DISORDERS AND DEVELOPMENTAL DISABILITIES



**Developed by the
Arizona Department of Health Services
Division of Behavioral Health Services**

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ISSUE: The treatment of individuals with Pervasive Developmental Disorders and Developmental Disabilities requires a comprehensive evaluation of life domains and service provisions by multiple agencies that approach interventions with unique perspectives, goals and desired results. A collaborative and integrated approach to care, with agreed upon values, priorities and expectations can promote improved treatment outcomes.

PURPOSE: To institute and maintain a process that promotes best practices for individuals with Pervasive Developmental Disorders and Developmental Disabilities that:

- Establishes protocols to effectively reduce target symptoms, improve overall functioning, and strengthen the community and family supports that enhance outcomes.
- Ensures that behavioral health services are coordinated and integrated with those provided by the Division of Developmental Disabilities (DDD), Child Protective Services (CPS) and all other agencies involved.

TARGET POPULATION: All Title XIX and Title XXI eligible children and adults diagnosed with Pervasive Developmental Disorders and/or Mental Retardation¹ and all individuals with both a serious mental illness and Pervasive Developmental Disorder and/or Mental Retardation.

BACKGROUND: ADHS/DBHS is committed to the provision of services through family focused practice and in the context of Child and Family Teams (CFT) or Adult Clinical Teams (ACT). In order to extend this commitment to children, adolescents and adults with Pervasive Developmental Disorders and/or Mental Retardation, service provision and planning should:

- Explore and document the strengths and needs of the individual and family;
- Establish and prioritize service goals;
- Identify the most appropriate services and supports necessary to meet those goals;
- Ensure that the services provided are of the intensity necessary to accomplish identified service goals;
- Describe a course of action encompassed in a written service plan developed by team members and informed by all involved agencies;
- Monitor the accomplishments of the individual and family; and
- Determine the responsibilities of all team members involved in these efforts.

PROTOCOL:

Assessment

The evaluation of both children and adults requires input from numerous sources and settings, structured and unstructured observations of behavior, and a thorough assessment of emotional, environmental, health (including dental), and social factors. Outcomes improve when behavioral health needs are identified and treated early. Assessment and services should be initiated at the first indication of behavioral concerns in order to limit the development of more severe

¹ Please refer to DSM –IV-TR for a comprehensive list of all disorders covered under these broad categories.

symptoms.

As with all behavioral health conditions, the assessment process should begin with the [ADHS/DBHS Behavioral Health Assessment](#). The underlying needs, strengths and resources of each individual and family must be continually reassessed and addressed on an ongoing basis in the context of a CFT or ACT. The assessment process must include input, when appropriate and available, from the individual being assessed as well as from schools, places of employment, other involved systems and family. As individuals with these disorders are often poor reporters of their own behaviors or symptoms, every attempt should be made to involve others capable of contributing meaningfully to the assessment process.

Parallel assessment and service planning processes like DES Family Decision Making or permanency planning meetings, DDD Person-Centered Planning Meetings and Individual Support Planning Meetings (ISP) and Individualized Education Plan (IEP) meetings in special education should be coordinated with CFT or ACT processes to avoid duplicative endeavors.

Compared to the general population, individuals with Pervasive Developmental Disorders and/or Mental Retardation are more likely to experience a variety of coexisting behavioral and physical health conditions. As symptoms may overlap, mimic or accentuate coexisting disorders, the following should be carefully assessed through psychiatric consultation, educational testing, primary care or specialty evaluations, and psychological testing, as indicated:

- Receptive language delay/disorder
- Expressive language delay/disorder
- Communication Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Learning Disorders
- Rett's Disorder
- Selective mutism
- Bipolar Disorder
- Schizophrenia with childhood onset
- Anxiety Disorders
- Mood Disorders
- Post Traumatic Stress Disorders
- Tic Disorders, including Tourette's
- Hearing impairment
- Endocrine Disorders
- Seizure Disorders
- Dental conditions
- Infections

- Constipation and other gastrointestinal disorders

For children, screening tools such as the Vineland Adaptive Scale may be given to parents and teachers at the initiation of the assessment. The Test of Nonverbal Intelligence (TONI) together with the Vineland is recommended if intelligence quotient (IQ) testing must be performed, especially between the ages of four and eight.

If standard verbal IQ tests are used after the age of eight, the psychologist should be familiar with the array of language deficits associated with these disorders. IQ testing prior to the age of eight is not recommended; an IQ prematurely diagnosed as low because of language deficits can lead to inappropriate labeling and lack of encouragement to parents and to their children as they develop. In all cases, testing in older children and adults should be completed with the use of a standardized culturally appropriate instrument.

Evaluators must be cognizant of the tendency for diagnostic overshadowing, which is the attribution of all symptoms or behaviors to an underlying Developmental Disorder or Pervasive Developmental Disorder, rather than looking for behavioral, medical, social, environmental, and other factors, and losing sight of the fact that individuals with these conditions suffer from the full range of psychiatric disorders that others do.

Psychiatric assessments and management for individuals less than 13 years of age should be performed by or in consultation with child and adolescent psychiatrists.

Service Planning

In collaboration with the family, caregivers, other primary social supports and other involved professionals, and in the context of CFT and ACT processes, a list of targeted symptoms, individual and family strengths, and treatment goals should be developed. The frequency and severity of target signs and symptoms should be documented at the initiation of therapy. Decreases in frequency and severity of target signs and symptoms, as well as enhancement of strengths, should be documented as therapy progresses. The CFT or ACT should determine realistic goals and a realistic pace for change.

Although communication and services must always be geared to the individual's level of comprehension and attention, it should never be assumed that the presence of Pervasive Developmental Disorders and/or Mental Retardation automatically precludes the individual's participation in goal setting or treatment planning, or would render any particular treatment modality ineffectual. Thus, the full range of covered services, including individual and group therapy, should be considered as potentially beneficial to any given individual.

Non-Pharmacological Approaches

All service provisions should be family focused and should rest on connections to natural supports, community based services and respect for the individual's unique cultural heritage and needs.

Given the unique and challenging needs of these individuals, RBHAs must designate Clinical Liaisons with specialized training, expertise, and invested interest in working with them.

“Specialized” Clinical Liaisons must:

- Be assigned to all cases for which Pervasive Developmental Disorder or Developmental Disability is diagnosed;
- Provide behavioral health consultation to the DD/ALTCS case manager;
- Coordinate behavioral health care with the DD/ALTCS case manager and other involved agencies, providers, or parties; and
- Work as an integral part of the Child and Family Team, or Adult Team.

I. Individual Counseling:

Cognitive-behavioral strategies may be used, with increased weight on the behavioral component, for lower functioning individuals. Achievable and relevant goals and objectives should be identified, and realistic expectations of progress established, as chaining and generalization of goals may occur slowly.

For individuals with verbal functioning, individual therapy can be very helpful to address feelings of isolation and to improve social adjustment. Play therapy or expressive therapies may assist those with impairments in verbal functioning.

For changes in life circumstances and other stresses that lead to emotional or behavioral disturbances, brief supportive treatments should be employed, as for any other individual, by clinicians who are competent to perform psychotherapeutic interventions geared to the developmental level of the individual.

II. Family Support:

Supports offered to family members may include:

- Support activities to assist the family’s adjustment to the individual’s disability,
- Developing skills to effectively interact with and/or manage the individual,
- Understanding the individual’s limitations,
- Understanding the treatment of behavioral health issues,
- Effectively utilizing the system, or
- Planning long term for the individual and the family.

III. Behavioral Assessment/Functional Analysis:

Challenging behaviors, like appropriate behaviors, are maintained by environmental, social and physical reinforcers. The clinicians’ task is to determine the function that the challenging behaviors play in the individual’s daily routine. This task is usually accomplished by conducting a “Functional Analysis.” A functional analysis includes an examination of the following:

- Antecedents and/or consequences that affect or control a behavior;
- Whether the behavior represents a deficit or an excess, or is situationally appropriate;
- Whether different behavior patterns occur with different situations;
- Possible schedules of reinforcements that maintain the behavior;

- An examination of environmental aspects and potential physical health issues that may relate to the challenging behaviors; and
- Potential reinforcers and potential alternative behaviors that may be used in the treatment plan to strengthen alternative behaviors.

Behaviors must be viewed in the situational and environmental context in which they occur and in relation to the influences that manifest before, during and after the behaviors. Antecedents may provoke behaviors naturally (like a loud noise causing an individual to jump) or through learning (recognizing, over time, that self-injurious behavior lead to increased attention). Events following a behavior can alter the likelihood of it recurring if it is positively or negatively reinforced. Thus, knowing antecedents and consequent events can be critical to understanding the reasons for challenging behaviors and to developing therapeutic interventions.

Behavioral assessments must also explore the effects that challenging behaviors have on caregivers, and who is most challenged by the behaviors. This allows service providers the opportunity to support and promote the most effective caregiver responses and an opportunity not only to change behaviors but also to shape and enhance the interpersonal environment in which they occur.

In order to conduct a functional analysis the clinician will be required to interview family members, other observers of the behaviors, and the individual as well as directly observe the individual while he/she is engaged in target behaviors.

The results of the functional analysis lead directly to the formulation of a treatment intervention by the CFT or ACT. Since interventions will need to occur throughout the day, family members, teachers or other direct care staff must understand the rationale for the method, the exact procedures to follow and the documentation that is required to measure the effectiveness of the interventions.

IV. Behavior Management:

The overall treatment strategy for behavioral interventions should emphasize the teaching of social, communication and cognitive skills to the individual and effective behavior shaping techniques to parents, to be used both during and after termination of therapy. Applied Behavioral Analysis Techniques and other behavioral management approaches should emphasize:

- The development and encouragement of constructive and effective ways for individuals to seek the attention they desire.
- Positive reinforcement for appropriate behavior and acknowledgment and reward of the individual's ability to establish age-appropriate autonomy to the extent possible.
- Identification and minimization of the antecedents to behavioral disruptions, agitation or self-injury by defining and utilizing positive or negative reinforcers.
- The enhancement of the individual's repertoire of social and communicative behaviors through social-pragmatic teaching.

- The careful documentation in the service plan of desired outcomes and measurable goals consistent with the individual's behavioral health needs.

Behavioral interventions must be coordinated with other agencies like DDD, which may be providing similar interventions as part of habilitation. Habilitation services use a variety of methods designed to maximize the person's abilities. Services typically are offered in the person's home or community and include activities specific to learning to become more independent.

Caregivers, family members and other providers in the individual's environment should be actively engaged, including involvement with "homework" assignments. Strategies must be integrated with other services and must be based on a thorough familiarity of the individual's environment, routine, strengths and limitations and the assured cooperation of the individual's caretakers, guardians, educators and other staff. As for all other service strategies, signs/symptoms of relapse or recurrence and exacerbating factors for co-occurring behavioral health disorders should be identified and strategies developed for coping with exacerbating factors.

Psychopharmacological Interventions

To promote the safe and efficient use of psychotropic medications in the treatment of Pervasive Developmental Disorders and Mental Retardation:

- All medication approaches must be consistent with the [ADHS/DBHS Provider Manual Section 3.15, Psychotropic Medication Prescribing and Monitoring](#) and, in the case of children or adolescents, [The Use of Psychotropic Medication in Children and Adolescents Practice Improvement Protocol](#).
- To rule out environmental causes of symptoms, the individual should demonstrate the targeted symptoms in at least two out of three settings before a psychopharmacological trial is considered.
- To rule out a medical or dental etiology for behavioral symptoms, consultation with the individual's primary care physician or dentist should be considered, especially in situations where the individual has little or no ability to verbally communicate his or her physical distress.
- In general, basic treatments for these conditions do not differ from that of the general population. If a general psychiatric condition is identified, the appropriate pharmacological approach for that condition should be employed, regardless of the presence of Mental Retardation or Pervasive Developmental Disorder. There are no psychotropic medication interventions that have been found to positively influence the specific symptoms of Mental Retardation or Pervasive Developmental Disorders. Medications are used to mitigate associated or coexisting concerning symptoms.
- It is important to consider that individuals with mental retardation are generally more sensitive to medications and more likely to experience side effects. This is particularly true in children. These side effects may, in turn, result in an increase in behavioral disturbance. Atypical antipsychotic-induced constipation, for example, may increase agitation in an individual with mental retardation and psychotic

symptoms. Starting psychotropic medications with low dosages and adjusting/increasing dosages slowly is commonly recommended.

- A large percentage of individuals with mental retardation or pervasive developmental disorder (in some surveys, over 33%) receive 3 or more psychotropic medications. For DD members with complex drug regimens, expanding the length of medication reviews, and their frequency to at least monthly, must be considered. This practice should yield improvements in family participation, diagnostic clarity, more appropriate use of medication and improved outcomes.
- The use of multiple medications should be evaluated carefully. Because of possible drug interactions, over-the-counter medications, non-traditional healing substances, herbs, and foods such as grapefruit juice should also be reviewed and assessed.
- For those individuals who do not have a separate identified psychiatric condition, but primarily have behavioral symptoms associated with their primary disorder, treatment should be symptomatic, using a thoughtful rationale to select an initial drug trial based on observed behaviors

Data Collection for Psychiatric and Behavioral Interventions

Data collection is a quantitative, systematic means of gathering specific information. Progress notes and anecdotal reports, although helpful, do not constitute objective data. Specific psychiatric symptoms and challenging behaviors must be objectively defined, quantified and tracked using empirical measurement methods in order to impartially monitor the effectiveness of behavioral interventions and/or psychotropic medication efficacy. These measurements include, but are not limited to, frequency, severity, duration, time sampling and rating scales. Treatment response must be linked to specific objectives and goals that are documented in the Behavioral Health Service Plan.

Physical Health Concerns

Behavioral health providers must assess physical health factors and coordinate all service provision with acute care providers, consistent with the following expectations:

- The psychiatrist, primary behavioral health professional or assigned clinician must ensure that there is coordination among all medical providers, including PCPs and psychological, pediatric, neurological, endocrinological and dental specialists and that service plans collaboratively developed.
- All relevant information, including the initial assessment and treatment plan, must be communicated to the primary care physician.
- As with behavioral health services, medical services are most effective when implemented as early as possible. Efforts to help a child learn and use language by age 8 are essential. These services should include a combination of behavioral and language based interventions, such as speech therapy, occupational therapy, sensory communication boards or picture boards, and evaluations for oral apraxias, expressive and receptive language abilities and hearing. Care and consultation between specialists should be coordinated with the client's Primary Care Provider (PCP). Referrals to appropriate specialists should be made as soon as deficits are identified.

Alternative Interventions

Although there remain limited well-controlled efficacy studies to support their use, a number of alternative interventions have demonstrated potential benefits to individuals with autistic spectrum disorders in some circumstances. The prescription of gluten- and casein- free diets has been beneficial to some individuals, as has the intake of Omega-3 fatty acid supplements. Omega-3 fatty acids are non-prescription and not on the ADHS medication list or RBHA formularies. Alternative interventions should be coordinated with the client's nutritionist and PCP and/or behavioral pediatrician.

Protection and Advocacy

While remaining aware of the incidence of self-injurious behavior in this population, reports to Child/Adult Protective Services (CPS/APS) must be made when there is suspicion of neglect or abuse, including medical or emotional. For open CPS or APS cases, the protective services case plan must be coordinated with the behavioral health services. CPS or APS case managers must be invited to all behavioral health services staffings and reviews.

Division of Developmental Disabilities

The Division of Developmental Disabilities provides support and habilitative services for individuals with significant functional limitations due to: Cerebral Palsy, Epilepsy, Mental Retardation and Autism. (Diagnoses of Pervasive Developmental Disorder not otherwise specified, Asperger's Disorder, Rett's Disorder and Childhood Disintegrative Disorder do not confer eligibility.)

Diagnosis is necessary but not sufficient for DDD eligibility; the individual must also have substantial functional limitations in at least three of seven domains of activities of daily living, which are directly attributable to the developmental disability. If individuals are found to be eligible for DDD-ALTCS, they may receive all Title XIX covered services. If individuals are eligible for DDD, but are not DDD-ALTCS or Title XIX/XXI eligible, services are provided based on availability and funding. The DDD non-ALTCS, Non-Title XIX/XXI individual may be placed on a waiting list if needed services or funds are not available.

If the individual is not yet enrolled in DDD, and mental retardation, autism, cerebral palsy or epilepsy is diagnosed, referral to DDD should be made for eligibility determination. An assessment and qualifying diagnosis made by a Behavioral Health psychiatrist or psychologist may offer sufficient clinical information for DDD to determine clinical grounds for eligibility, provided that the symptoms of the developmental disability diagnosis are adequately recorded in the documentation of the evaluation and the symptoms and diagnoses meet the criteria that required to confer eligibility.

If DDD provides services, such services must be coordinated with the behavioral health services. DDD Support Coordinators should be invited to all CFT meetings, ACT meetings and medication reviews. All relevant information, including the initial assessments and treatment plan, must be communicated to DDD to ensure coordination of services. Per the ADHS/DES/DDD Intergovernmental Agreement (IGA) and Operational Procedure Manual, for DDD/ALTCS individuals, the DDD support coordinator is the lead Case Manager.

Education

The parent/legal guardian will be advised to request the school district's cooperation. This will include the school's participation in the initial and ongoing evaluation and interventions. The parent may also request the school to provide a comprehensive educational evaluation to determine the need for additional support services such as occupational, physical, or speech therapy, special education eligibility, IQ testing, or an accommodation assessment. The behavioral health professional should participate in the development of the Individual Education Program (IEP) to assist the school in maintaining the individual in the least restrictive individual educational setting.

Vocational Rehabilitation

Vocational training may be available through the school to individuals who are under the age of 16 and designated as emotionally handicapped (EH). For persons 16 and over, referral to VR services should be considered and services coordinated, if appropriate.

Clinical Supervision

Regularly scheduled and predictable clinical supervision should be provided to Behavioral Health Technicians and Behavioral Health Professionals. Individuals with expertise in positive behavioral support techniques and experience with Developmental Disability and Pervasive Developmental Disorder populations can assist providers in modifying and adapting therapeutic interventions to their unique needs. All clinicians can benefit from added assistance in adjusting counseling to shorter attention spans, limited language skills, and difficulties retaining information for expected periods of time.